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For Some With Intellectual Disabilities, Ending Abuse Starts With Sex Ed

By JOSEPH SHAPIRO (/PEOPLE/JOSEPH-SHAPIRO) • JAN 9, 2018

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A participant helps Park hang the agenda on the wall at the start of class. BRIANNA SOUKUP FOR NPR



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Editor's note: This report includes graphic and disturbing descriptions of sexual assault.

In the sex education class for adults with intellectual disabilities (http://www.momentumme.com/relate.html), the material is not watered down. The dozen women and men in a large room full of windows and light in Casco, Maine, take on complex issues, such as how to break up or how you know you're in an abusive relationship. And the most difficult of those issues is sexual assault.

Katy Park, the teacher, begins the class with a phrase they've memorized: "My body is my own," Park starts as the rest join in, "and I get to decide what is right for me."

People with intellectual disabilities are sexually assaulted at a rate more than seven times that for people without disabilities. NPR asked the U.S. Department of Justice to use data it had collected, but had not published, to calculate that rate.

At a moment when Americans are talking about sexual assault and sexual harassment, a yearlong NPR investigation finds that people with intellectual disabilities are one of the most at-risk groups in America.

"This is really an epidemic and we're not talking about it," says Park (https://www.relatewithkatypark.com/), a social worker who runs arts and wellness programs for Momentum, an agency based in Maine that provides activities in the community and support services for adults with intellectual disabilities. Those high rates of abuse — which have been an open secret among people with intellectual disabilities, their families and people who work with them — are why Park started this class about healthy relationships and healthy sexuality.

Because one of the best ways to stop sexual assault is to give people with intellectual disabilities the ability to identify abuse and to know how to develop the healthy relationships they want.

"Let's talk about the positive parts of being in a relationship," Park says, holding a marker while standing at a whiteboard, at the start of the class. "Why do we want to be in a relationship?"

"For love," says one man. "And sexual reaction."

"Romance," adds a woman.

"How about support?" asks Lynne, a woman who speaks with a hushed voice and sits near the front of the class.

"Having support, right?" Park says, writing the word on the board. "We all want support."

From working with the men and women here, Park realized they want to have relationships, love and romance. They see their parents, siblings and their friends in relationships. They see people in relationships when they watch TV or go to the movies. They want the same things as anyone else.

But it's harder for them. When they were in school, most of the adults in this room say, they didn't get the sex ed classes other kids got. Now, just going on a date is difficult. They probably don't drive or have cars. They rely on public transportation. They don't have a lot of money. They live at home with their parents or in a group home, where there's not a lot of privacy.

And then there's the one thing that really complicates romance for people with intellectual disabilities: those high rates of sexual abuse.

"Oftentimes, it actually is among the only sexual experience they've had," says Park. "When you don't have other healthy sexual experiences, how do you sort through that? And then the shame, and the layers upon layers upon layers."

This class, she says, is about "breaking the chain, being empowered to say, 'No. This stops with me.' "

"I think people take advantage"

The women and men come to Momentum during the week for different programs. They go kayaking and biking; they go to the library and do volunteer work at the local food bank. There's a range of disability here. You can look at some of the men and women — maybe someone with Down syndrome — and see they have a disability. Others, even after you talk to them, you might not figure out they have an intellectual disability.

Like one small woman with short, choppy dark hair, streaked red.

She's 22 now, but when she was 18, her boyfriend was several years older. She says he was controlling. He didn't let her have a cellphone or go see her friends.

"He was strangling me and stuff like that," says the woman. (NPR is not using her name.) "And he was, the R-word — I hate to say it, but rape." She says he raped her eight times, hit her and kicked her. "So I don't know how I'm alive today, actually. He choked me where I blacked out."

She thinks she was an easy target for him, because of her mild intellectual disability. "I think people take advantage," she says. "They like to take advantage of disabilities. I have disabilities, not as bad as theirs. But I think they like to take advantage, which is wrong. I hate that."

She says the class helped her better understand what she wanted, and had a right to, in a relationship. She's got a kind and respectful boyfriend now.

Her friend Lynne listens and says she would like to find a boyfriend. But in her past, she has experienced repeated sexual abuse.

She talks about a time when she was 14 and "this older guy that knew us" forced her to have sex. She says she told people but no one believed her. The next year, when she was 15, she was sexually assaulted — this time by a boy at her school. "I was trying to scream," she says, "but I couldn't because he had his hand over my mouth, telling me not to say anything to anybody."

Lynne, who is 38, says those rapes and others left her unable to develop relationships. "I couldn't trust anyone," she says. Lynne (NPR has agreed to identify her by her middle name) says this class has helped her realize she wants a real, romantic relationship and has taught her how to better find one.

"There's a lot of loneliness"

Katherine McLaughlin, a New Hampshire sex educator, developed the curriculum used by Momentum (http://disabilityworkshops.com/). She wrote it so that it uses concrete examples to describe things, to match the learning style of people with intellectual disabilities. It shows pictures and uses photographs.

McLaughlin says the main desire of adults with intellectual disabilities is to learn "how to meet people and start relationships. There's a lot of loneliness."

That loneliness leaves them vulnerable to getting into abusive relationships, she says, or to rape.

Sometimes, especially when they're young, they can't name what happened to them as a sexual assault. Because they didn't get the education to identify it. "We don't think of them as sexual beings. We don't think of them as having sexual needs or desires," McLaughlin says. "Often they're thought of as children, even when they're 50 years old."

Sheryl White-Scott, a New York City internist who specializes in treating people with intellectual disabilities, estimates that at least half of her female patients are survivors of sexual assault. "In my clinical experience, it's probably close to 50 percent, but it could be as high as 75 percent," she says. "There's a severe lacking in sexual education. Some people just don't understand what is acceptable and what's not."

Most of the women and men at the class in Maine say they didn't get sex ed classes, like other kids, when they were in school. Or if they did, it was the simplistic warnings, like the kind given to young children. "It's easy to fall back on 'good touch-bad touch' sex ed," says Michael Gill

(http://disabilitystudies.syr.edu/blog/2015/12/11/faculty-profile-michael-gill/), the author of *Already Doing It: Intellectual Disability and Sexual Agency*. "That's a lot of what they get." And the usual warning about "stranger danger" can be unhelpful, because it's not strangers but people they know and trust who are most likely to assault them.

Most rapes are committed by someone a victim knows. For women without disabilities, the person who assaults them is a stranger 24 percent of the time. NPR's data from unpublished Justice Department numbers show the difference is stark for people with disabilities: The abuser is a stranger less than 14 percent of the time.

"Parents get this; professionals don't," says Nancy Nowell, a sexuality educator with a specialty in teaching people with developmental disabilities, an umbrella term that includes intellectual disability but also autism.

Parents have significant reason to worry: Figuring out what's a healthy relationship is difficult for any young person, and it can be even trickier if a person has an intellectual disability. People with intellectual disabilities are vulnerable to problems from rape to unwanted pregnancy. Some people with intellectual disabilities marry. A small number have children — and rely upon family or others to support them as parents.

Still, says McLaughlin, parents often are reluctant to talk to their children with intellectual disabilities about sex. "Parents often feel, if I talk about it they will go and be sexual," she says, and they fear that could make them targets for sexual assault.

But educators such as McLaughlin, Gill and Nowell argue the reverse: that comprehensive sexuality education is the best way to prevent sexual assault. "If people know what sexual assault is," says Gill, an assistant professor of disability studies at Syracuse University, "they become empowered in what is sexuality and what they want in sexuality."

Respect

Gill argues that a long history of prejudice and fear gets in the way. He notes early 20th century laws that required the sterilization of people with intellectual disabilities. That came out of the eugenics movement, which put faith in IQ tests as proof of the genetic superiority of white, upper-class Americans.

People with intellectual disabilities were seen as a danger to that order. "Three generations of imbeciles are enough," Supreme Court Justice Oliver Wendell Holmes famously wrote in a 1927 opinion (https://www.npr.org/2017/03/24/521360544/the-supreme-court-ruling-that-led-to-70-000-forced-sterilizations) that ruled the state of Virginia could forcibly sterilize a young woman deemed "feebleminded."

Carrie Buck was the daughter of a woman who lived at a state institution for people with intellectual disabilities. And when Buck became pregnant — the result of a rape — she was committed to a state institution where she gave birth and was declared mentally incompetent to raise the child. Buck was then forcibly sterilized to prevent her from getting pregnant again. There was evidence that neither Buck, nor her daughter, Vivian, was, in fact, intellectually disabled. In the first half of the 20th century, impoverished women who had children outside marriage were often ruled by courts to be "feebleminded."

There was another myth in popular culture that people with intellectual disabilities were violent and could not control their sexual urges. Think about that staple of high school literature classes, John Steinbeck's *Of Mice and Men*. The intellectually disabled Lennie can't control himself when the ranch hand's wife lets him stroke her hair. He becomes excited, holding her too tight, and accidentally strangles her.

The class in Maine aims to help these adults know what's a healthy relationship and how to communicate how they feel about someone.

The main way this class differs from a traditional sex ed class is that — to help people with intellectual disabilities learn — the material is broken down and spread out over 10 sessions. Each class lasts for 2 1/2 hours. But the adults in the class are completely attentive for the entire session.

They do take a couple of very short breaks to get up and move around, including one break to dance. Everyone gets up when Park turns on the tape recorder and plays — just right for this group asking to be treated like adults — Aretha Franklin singing "Respect." There is joyous dancing and shouts. And when the song is over, they go back to their seats and get back to work.

Meg Anderson assisted with reporting for this story.

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DAVID GREENE, HOST:

An NPR investigation has revealed an epidemic of sexual assault against people with intellectual disabilities. This morning, we're going to hear about one part of a solution - sex ed classes. This is because the first step is to name what is abusive. And just a warning here - there are descriptions of sexual assault in this report from NPR's Joseph Shapiro.

(CROSSTALK)

JOSEPH SHAPIRO, BYLINE: We're in a large room - it's full of windows and light - at a center in Casco, Maine, run by a group called Momentum that works with people with intellectual disabilities. They come here during the week for different programs. They go kayaking and biking. They go to the library and do volunteer work at the local food bank. And on this morning, a dozen adults evenly split between men and women take chairs around the large room.

KATY PARK: Wake your bodies up. Great. Keep you motivated.

SHAPIRO: They're here for the sex education class.

PARK: All right, let's do a little brainstorming first. Let's talk about...

SHAPIRO: It's a class about healthy relationships and healthy sexuality.

PARK: Why do we want to be in a relationship?

SHAPIRO: That's the teacher, Katy Park. She's holding a marker and writing the answers on a whiteboard.

JULIAN: For love.

PARK: For love.

JULIAN: And sexual reaction.

PARK: So yeah, love and sex - right? - pleasure. What else?

SHAPIRO: There's a range of disability here.

PARK: How about romance?

ZACH: Yeah.

UNIDENTIFIED WOMAN #1: Romance.

ZACH: There's nothing wrong with that.

PARK: Nothing wrong with that.

KACHINA: (Laughter).

SHAPIRO: You can look at some of the men and women - maybe someone with Down syndrome - and see they have a disability. And others, even after you talk to them, you might not figure out they have an intellectual disability, like this woman.

UNIDENTIFIED WOMAN #2: Yeah, he was strangling me and stuff like that.

SHAPIRO: For her, like for others in this class, there's something that gets in the way of relationships. It's her own history of sexual assault.

UNIDENTIFIED WOMAN #2: He was - the R-word - I hate to say it, but rape.

SHAPIRO: The R-word she's talking about, the word she says softly, is rape.

UNIDENTIFIED WOMAN #2: He did that to me. I've been that eight times, so I don't know how I'm alive today, actually. And he choked me where I almost - I blacked out. He used to hit me, kick me.

SHAPIRO: We're not using her name. She's 22 now. She was 18 then, and her boyfriend was several years older. She says he was controlling. He didn't let her have a cellphone or go see her friends. And she thinks she was an easy target for him because of her mild intellectual disability.

UNIDENTIFIED WOMAN #2: I think people, like, take advantage. They like to take advantage of disabilities because I have disabilities not as bad as theirs. But I think he liked to take advantage, which is wrong. I hate that.

SHAPIRO: She says the class helped her better understand what she wanted and had a right to in a relationship, and that she's got a kind and respectful boyfriend now.

PARK: So let's try it where I start it and then you guys follow, right? My body is my own.

UNIDENTIFIED STUDENTS: My body is my own.

PARK: And I get to decide what is right for me.

UNIDENTIFIED STUDENTS: And I get to decide what is right for me.

SHAPIRO: The material in this sex ed class is not watered down for these people with intellectual disabilities. They take on complex issues, like breaking up and abusive relationships. The main accommodation is that the material is broken down and spread out over 10 sessions, and each class lasts for 2 1/2 hours. The people here are completely attentive. They do take a couple very short breaks to get up and move around.

PARK: OK, I'm going to start the music.

SHAPIRO: And at one point, they take a break and get up and dance.

(SOUNDBITE OF ARETHA FRANKLIN SONG, "RESPECT")

SHAPIRO: Everyone in this room says they want love and relationships. They see their parents, their siblings, their friends in relationships. They see it when they watch TV and go to the movies. They want the same things as anyone else. But the men and women in this room know that in the eyes of the rest of the world, they're not seen as people who are going to find love, romance or sex. They're considered childlike or incapable or just uninterested.

(SOUNDBITE OF SONG, "RESPECT")

ARETHA FRANKLIN: (Singing) R-E-S-P-E-C-T - find out what it means to me.

SHAPIRO: When they were in school, they probably didn't get the sex ed classes the other kids got. And now that they're adults, it's harder for them, compared to other people, to develop relationships. Just going on a date is hard. They probably don't drive or have cars. They rely on public transportation. They

don't have a lot of money. They live at home with their parents or in a group home where there's not a lot of privacy.

PARK: Nice moves, guys.

(APPLAUSE)

SHAPIRO: And then there's that history of sexual assault - the thing that really complicates relationships for people with intellectual disabilities. They suffer some of the highest rates of sexual abuse. Our NPR investigation used unpublished federal crime data and found people with intellectual disabilities are sexually assaulted at rates at least seven times the rate for people without disabilities.

PARK: Oftentimes it actually is among the only sexual experience they've had.

SHAPIRO: That's Katy Park, who teaches the class.

PARK: When you don't have other healthy sexual experiences, how do you sort through that?

SHAPIRO: And that's why Park brought the sex ed curriculum because the best way to stop sexual abuse is to give these men and women the ability to identify what's abuse and then how to stop it.

PARK: And then it's breaking the chain, being empowered to say, no, this stops with me.

SHAPIRO: One woman in the class, Lynne, says she'd like to find a boyfriend. She's 38 now. But in her past, she's experienced sexual assault.

LYNNE: All my friends were with this guy, this older guy that knew us. They wanted us to do some stuff, and I didn't want to do it. And they just forced us to do it.

SHAPIRO: How old were you at the time?

LYNNE: Fourteen.

SHAPIRO: Fourteen.

And the next year when she was 15, she was sexually assaulted again, this time by a boy at her school.

So were you able to tell somebody about that one?

LYNNE: No, I had to - I was trying to scream but...

SHAPIRO: Trying to scream.

LYNNE: Yeah.		
SHAPIRO: And?		
LYNNE: To get help.		

SHAPIRO: Yeah.

LYNNE: But I couldn't because he had his hand over my mouth telling me not to say anything to anybody.

SHAPIRO: Those rapes and others left Lynne - and we've agreed to identify her by her middle name - unable to have relationships.

LYNNE: I couldn't trust anybody.

SHAPIRO: She says this class has helped her realize she wants a romantic relationship and that it's something that's maybe finally possible for her now.

LYNNE: By taking the class, I can really try to trust people to like me and then they can just get to know people instead of just rushing into a relationship.

SHAPIRO: Lynne is trying to turn around a history of repeated sexual abuse. It's her personal history, but it's also the common story of people like her with intellectual disabilities across America. Joseph Shapiro, NPR News.

(SOUNDBITE OF SEAS OF YEARS' "LIKE TALL SHIPS UPON THE SKY") Transcript provided by NPR, Copyright NPR.

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